Op-Ed

When does primary care turn into palliative care?

Rarely does it occur at a discrete point in time, but primary care physicians must be alert to their role in the transition see also p 197

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Why should primary care clinicians play a role in palliative medicine? A generalist colleague put it this way: "I just don't understand all this attention to end-of-life care. I don't have that many patients who die." On further questioning, it became clear that of the 5 patients of this physician who died last year, 2 died in home hospice where their care was directed by an oncologist, 2 died in nursing homes under the direction of the nursing home physician, and 1 died in an intensive care unit directed by an intensivist. Thus, that this physician does not feel herself to be on the front line of care of the dying is understandable.

Yet, primary care physicians have a critical role in guiding patients with chronic and life-limiting illnesses through the early phases of an illness that will eventually become terminal. These physicians are responsible for the patient-physician communication and medical decision making that occur—or should occur—early in the illness. How well these physicians do with this communication and decision making has an important effect on patients' experiences as they are dying. For example, patients with cancer who unrealistically overestimate their survival, due in part to a lack of communication with their physicians, are more likely to die under mechanical ventilation or after an attempt at cardiopulmonary resuscitation.[1]

The systems of care in which physicians work can have a powerful effect on the quality of end-of-life care, and primary care physicians could have an important role in ensuring that "the system" does not get in the way of personalized care. One of the problems with hospital-oriented care is that it tends to focus on responding to acute exacerbations of illness, rather than on an integrated approach incorporating preventive, curative, and palliative care. The strong influence that systems of care can exert on end-of-life care was demonstrated in the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), which studied seriously ill patients admitted to the hospital. In SUPPORT, the strongest predictor of whether patients were discharged to home hospice care was not patient prognosis or physician knowledge of patient preferences for end-of-life care, but rather the number of hospital beds in the region.[2] In other words, the more hospital beds that were available, the easier it was for physicians to keep dying patients in the hospital. Here, the system of care was more influential in discharge to home hospice than whether a patient's physician was a primary care generalist or a specialist. Primary care providers should remain alert to this powerful influence of care systems because it may detract from the provision of appropriate end-of-life care.

In intensive care units, the switch from curative to palliative care is often dramatic and easy for clinicians to identify.[3] In primary care settings, though, a patient's transition to palliative care is usually less dramatic, discrete, and identifiable. Trying to identify a discrete switch point to palliative care is probably not a helpful strategy for primary care physicians. The Institute of Medicine defined palliative care as "seek[ing] to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure."[4] We contend that, for primary care physicians, the essential skill is to recognize when key issues in palliative care present themselves, because this often occurs long before a specialized palliative care service (such as hospice) is involved.

The key palliative care issues that primary care physicians encounter are the focus of a series of evidence-based case reviews that begins with an article in this issue of *wjm* (p 197). We have selected cases illustrating clinical situations familiar to primary care clinicians that may serve as markers for when palliative care should become a central feature of standard medical care. The key issues include topics such as symptom assessment and management, communication about prognosis and treatment preferences, and treating depression in seriously ill patients. Not all the cases concern end-of-life care because palliation may be needed well in advance of the dying process.

As palliative care experts argue that palliative care ought to begin earlier in illness, primary care physicians may feel that this emphasis on palliative care is overstated. As one of our colleagues joked, "When is palliative care supposed to start—at birth?" But at some point, palliative care issues take a central role in the care of a patient with a chronic, life-limiting disease. Studies suggest that major gaps exist between what patients at the end of their life want from their medical care and what they receive. Patients say they want to die at home, but 60% to 80% die in an institution.[4] They say that pain and symptom control are essential, but 70% of outpatients with advanced cancer have moderate to severe pain.[5] They say they want to relieve the burdens imposed on their families by their illnesses, but a third of families caring for a dying person spend all their savings on providing care.[6]

To address these gaps, physicians need to broaden their

field of competence. High-quality palliative care requires cognitive skills familiar to physicians, such as differential diagnosis or evaluating published evidence, and we plan to cover these core skills in our series. But high-quality palliative care also requires affective skills, such as communication and emotional support,[7] which will also be discussed. We hope that the series will enhance physician competence in both the technical and emotional aspects of palliative care.

What is the incentive for primary care physicians to improve their skills in palliative care? Physicians caring for dying patients say that this is some of the most meaningful work they do. "Surrounded by dying young parents," writes Peter Selwyn, "I slowly came to understand what it meant to have a father, and to be one. This process of awakening . . . was for me, a journey of healing . . . ."[8] The meaning of the work physicians do in guiding a patient through illness to death can make a hectic day worthwhile.[9]

Joan Oorbeck

Cognitive skills must be coupled with quality communication and emotional support when caring for patients with chronic and life-limiting illness

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